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ABSTRACT

The report examines issues in the "aging out" process, in which handicapped youth 21 years of age are no longer eligible for publicly funded residential, educational, and child care facilities. Procedures involved in New York's transitional care and maintenance programs are noted, and new concepts regarding the extent of society's commitment to the education of disabled citizens are addressed. Specific examples in Onondaga County are illustrated. The importance of redirecting educational and vocational thrusts to community-based approaches is discussed. Aging out is traced to inadequate educational, vocational, and residential strategies. Community-based, community-oriented instruction is offered as the alternative for severely disabled individuals. A section examines ways in which the community-based alternative could strengthen the effectiveness of special education in Onondaga County and the state. Short-term and long term community based strategies are considered. (CL)

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"CRISIS AT THE CROSSROADS"

A look into the aging out crises in Onondaga County

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Dedicated with eternal love and admiration
to my father,
Joseph V. Miele, Sr.

and to all those who refuse to be bound
by tradition and compromise, but instead
courageously strive for progress and justice.

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ABSTRACT: Aging out refers to the situation arising when mentally retarded, developmentally disabled or youth with other handicapping conditions reach 21 yeas of age, and are turned out of publicly funded residential, educational, and child care facilities (Developmental Disabilities Digest, 1984). This report examines the aging out issue in Onondaga County, and discusses current efforts by the state of New York to address the problem. A major effort in this direction has been the recent appropriation of monies for "transitional care and maintenance," which are targeted for those aging out of residentially based schools. A forecast is developed of the number of individuals likely to receive this aid within the next three years, and of the subsequent costs to the county and state. A number of recommendations and strategies for easing and preventing the grave affects of aging out are offered.

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PREFACE

This report begins with the story of a young man named David[1]. Though he recently turned twenty, his dirty blond hair and deep green eyes could pass him off as being twenty-five or twenty-six. When you first meet him you almost always come up against a piercing stare which just as readily gives way to a smile. Those who know him can quickly list his favorite ice cream flavors, and will swear he can shoot 90% of his shots on the basketball court. He has traveled a long hard road for one so young, for he has had to live with and overcome his label of mental retardation.

At an early age David became very aggressive towards most everyone around him, especially other children. Quickly and quietly, David's "severe emotional problems" led him out of his home and community and into a small, private residential school. Nearly five hours from his home, the school was situated in a quaint section of rural New York. "The country will be good for him," reassured friends and neighbors, though David's parents were never quite comfortable about his placement there. "They specialize in children like David, - the program is full of them," hinted the specialists sitting in on David's core meeting at the nearby grammer school. His parents listened to their advice, and followed their recommendations. David only knew he was leaving home.

Twelve years later, David still lashes out at people occasionally; usually at staff who try to physically guide him back into reading or singing groups. For this he is directed to a corner where he must sit quietly for several minutes. But for the most part, in school, David demonstrates few really obnoxious or threatening behaviors. On his occasional trips into the community, however, he becomes easily overwhelmed by the sounds, smells, and activities because he is still so unaccustomed to them. While the staff assigned to David loves working with him in the classroom, they feel insecure in these community settings and tend to react strongly to some of the things he says and does there. The school does have a program for older students trying to develop community living skills. David has been in it for almost two years, and has made what is viewed as "concrete improvements." Still, it is insisted that David needs a great deal of additional training before he can successfully move out into the community. Certainly more than can be offered in nine remaining months until his twenty-first birthday, at which time David will no longer receive funding for his program and will be forced to leave.

David's parents received notification of their son's impending removal from the school while sifting through a Wednesday's pile of bills and assorted junk mail. They tried in vain to hold back their tears while they sat in quiet desperation and fear for their son and for themselves. Unlike their other three

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[1] This is a composite case, not true in the sense that there is actually a David, but reflective of the children, and young adults, represented in this report.

children, David was in some ways a stranger to them. They loved him as parents love a child, but their adult son knew them mostly through holiday visits and weekly phone calls. They attended his educational meetings, and regularly kept in touch with the professionals and other staff at the school. But the togetherness most families take for granted, was just not there.

They quickly blamed themselves for sending their son away in the first place, but soon guilt gave way to anger. Where were the professionals who twelve years earlier were so positive David needed a placement so far from home? What was the school's position; or was their concern only with new students and new tuitions? Where was David to go now, and how was he to adjust to a family and community which only knew of him through the files at the local school offices? How could they take care of another child when they themselves were just making ends meet? "How did things come to this," they wondered later that night, as they dimmed the lights in their bedroom. They closed their eyes, yet knew this would be the first of many sleepless nights.

In reality, David is a composite character; drawn from several case histories. His story, however, is very real for countless numbers of America's disabled young adults and their families. The scenes in this story are replayed across every corner of the nation. While the names and faces change, the feelings of despair, anger, and helplessness are the same...sadly, so is the usual outcome for "aging out" victims.

This is a professional report; but it is also a story. In a technical sense, it discusses numbers and costs, mandates and limits of responsibility, and other general issues surrounding the aging out situation in Onondaga County. It describes the county and state's attempts to provide assistance for those students (and their families) aging out.

While it addresses general issues critical to the entire aging out population, special attention is devoted to those who will soon age out of residential programs such as the New York School for the Deaf, Batavia, etc. These individuals are potentially eligible for "transitional care and maintenance

funding" monies to continue their current programs while alternative placements are secured. The rationales, guidelines, and costs of this "TCM" funding are reviewed and evaluated in detail.

In this context, I have remained within the more common approaches to departmental reports. By this, I mean that one or more groups of data are followed by their respective analyses, and interpretations. This methodology works fine when dealing solely with facts and figures. But it does little justice to the daily and long-term problems encountered by all those who age out, including those not fortunate enough to qualify for transitional care and funding.

For this reason, "Crises at the Crossroads" needed also to be a story... It is a story of our success and failure, of what we have worked to achieve, and what we must work even harder to obtain. It is a story of morals and values, and of responsibility. Most importantly, it is a story about those persons who face aging out. While their actual names cannot be mentioned, it is very much the story of their future and unlike most stories, we, the readers, can write the ending as we see fit. We can write about a future of meaningful, enriching lives, where disabled persons never stop reaching for success and happiness or we can continue bearing witness to lives abandoned; as wanting and forgotten as an unfinished novel. We can write about a future where emphasis falls on abilities, not disabilities. Or we can write of futures where failure is anticipated and subscribed to in such a way as to make it seemingly inevitable. We can write of futures where the disabled and non-disabled enjoy a more comfortable and positive interactions with each other. Or we can write of futures where they live obscurely; always sadly different, and always wondering about missed opportunities and lost dreams.

III

There are those who would quickly dismiss this admittedly harsh perspective as being overdramatic, misleading, and even unnecessary. To them, aging out is viewed as a natural, albeit unfortunate, limitation of our educational, vocational, and residential philosophies; and of a society which simply cannot provide for every disabled person at every age. Yet, not so long ago, the same position confronted those calling for deinstitutionalization and mainstreaming. Despite great resistance and skepticisms, these progressive policies are now well ingrained in what we call "special education." Now, radical changes are again in the air. One is the idea that society's commitment to the educational needs of its disabled citizens should not be constrained but fluid. That literally, it should embody a lifelong commitment, and not be subject to specific age restrictions. Within this approach, disabled adults would continue to benefit from educational programs and services contoured around their needs. Of course, specific elements of programs would be changed or discontinued (that is, proponents aren't suggesting adults remain in school with children) but the commitment to education would not be abandoned simply because recipients reach the age of 21 years.

Naturally this concept involves substantial changes in both thinking and methodologies. Naturally, many will rally around the position that this "lifelong learning" philosophy is well intentioned but given present financial, programmatic and personal resources, simply unfeasible. This pretext holds little merit for the growing numbers of parents and professionals calling for immediate and substantial aging out reforms. Their concerns are urgent and deep-rooted; stemming not only from the perceived abandonment of meaningful programs and services, but also from a fundamental dissatisfaction with tradi-

tional approaches to special education. Indeed, with respect to severely handicapped individuals,[2] many would insist these approaches are failing miserably. It is not that the severely disabled are the only ones facing aging out, but they are certainly one of the populations aging out hits the hardest. And whereas the underlying reasons would have formally focused soley on disabilities of these students, they have now begun to shift onto the educational processes involved.

Therein lies the second critical idea being forwarded, namely that present educational and vocational strategies for individuals with severe disabilities must be retailored to accurately and effectively address their unique needs. (Brown et al., 1983a, 1983b, Baumgart et al., 1982). Proponents of this reevaluation effort have found new hope in the growing body of research targeted at those with severe and profound disabilities; much of which has shattered many long held preconceptions about this group. Most striking is research that points out the benaficial effects of (1) intergrating students with severe disabilities

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2 The label severely handicapped refers to students who are among the lowest intellectually functioning 1% of th school-aged population. This 1% range includes students who also have been ascribed such labels as psychotic, autistic, moderately/severely/profoundly retarded, trainable level retarded, physically handicapped, multiply handicapped,and deaf/blind. Certainly a student can be ascribed one or more of these labels and still not be referred to as severely handicapped for purposes here, as s/he may not currently be functioning intellectually within the lowest 1% of a particular age. (Brown, L., Ford, A., Nisbet, J., Sweet, M., Donnellan, A., Gruenwald, L. (1983). Opportunities available when severely handicapped students attend chronological age appropriate regular schools. The Journel of the Association for Persons with Severe Handicaps, 8, 24.

into public schools with non-disabled peers, (Brown et al., 1979, 1983a; Donaldson, 1980; McHale and Simeonsson, 1980; Stainback and Stainback, 1981; Voeltz, 1980) (2) redirecting and restructuring educational programs so as to encompass "community skills training" as opposed to "pre-academic skills" training, (Brown, Nietupski, and Hamre-Nietupski, 1976; Baumgart et at., 1982; Brown et al., 1978; Ford, Johnson, Pumpian, Stengert and Wheeler, 1980), and (3) redirecting and restructuring vocational training programs so as to promote integrated, and non-sheltered employment as opposed to traditional sheltered workshop settings. (Brown, et al., 1983b; Hill and Wehman, 1982; Wehman et al., 1982). Even the most conservative interpretation of this research would suggest that a reconsideration of present strategies is in order. For most students with severe and profound disabilities, including those in Onondaga County, still experience traditional modes of teaching, whether in residential programs, seperate nonintergrated schools, and in public schools. They usually receive their teaching in homogeneous settings with other severely disabled persons (accompanied by few if any non-disabled peers). In similar fashion, they receive their vocational training mostly in "sheltered", segregated environments. Yet, when they reach age 21, great numbers are still unprepared for community living or competitive work, and subsequently have the greatest difficulty finding placements in these areas. For them, aging out also means "fading out," for without opportunities for more independent and normalized environments, many return and/or remain home, where their current skills can easily deteriorate until they need complete and full time care. They then can become a great burden to their families, not for lack of love and understanding, but for the sheer emotional and financial strain involved with continual, dayround care. For parents who are sickly, or otherwise unable to provide such care, the situation grows even more desperate. Like David's parents, they do not want to see all

that has been invested in their child's future, be for nothing. They are concerned about what is best for their child, not "convenient" or "acceptable" compromises contoured around financial and policy trends.

With that in mind, this report reviews some of the traditional pathways embodied in the present special education process. More specifically, it explores how and why so many disabled persons "fail" the criteria used to determine eligibility for community living and non-sheltered employment. An effort is made to isolate and expose the specific methodologies, approaches, and strategies which often make failure almost inevitable.

External factors, such as the limited growth and availability of community placements, societal attitudes, etc., are also examined. Individually and in unison, these issues will provide the foundation for the ideas and recommendations presented. While I've not ignored financial concerns, neither have I been governed by them. I've begun around the needs of these individuals, and have worked outward. But this should not be construed to mean that, providing the best possible programs and services, and being cost-effective, are mutually exclusive. Just the opposite is true. (Blatt, 1981; Brown et al., 1983b). The directions I offer reflect substantial savings now, and in the future. Most importantly, they'll provide opportunities for richer, more satisfying lives; for those who otherwise would never have the opportunities we so casually take for granted.

Joseph V. Miele, Jr.
Syracuse, New York
August, 1984

SUMMARIES AND RECOMMENDATIONS OF THIS REPORT

This report was originated by the Onondaga County Department of Social Services to begin defining the major concerns and issues surrounding the aging out crisis in Onondaga County. This term refers to the situation of individuals being forced out of publicly funded educational and vocational training programs because they have reached the age of 21 years. In many cases, these individuals have great difficulty finding acceptance into meaningful alternative placements; many have no recourse but to remain homebound. The State of New York has recently taken greater interest in the aging out crisis. Efforts have been directed at providing referral and other programmatic assistance to families of aging out victims. The New York State Department of Social Services, along with its county branches are currently offering financial assistance to certain aging out victims. This "Transitional Care and Maintenance" (TCM) funding is directed solely at those aging out of residential schools. The Summaries and Recommendations of this report follow.

1. UTILIZE TRANSITIONAL CARE AND MAINTENANCE DOLLARS FOR THOSE CURRENTLY "AGING OUT" TO DEVELOP INDIVIDUALIZED SERVICES PLANS (ISPs) IN LOCAL COMMUNITY ENVIRONMENTS INSTEAD OF FUNDING LONG-TERM CARE IN RESIDENTIAL SCHOOLS.
   A. Long term care in residential schools for these individuals appears neither educationally sound nor financially feasible. Therefore, transitional care and maintenance funding should be viewed as a short-term intervention strategy, and not a final solution to the aging out crises.
   B. These individuals need to return to their families, neighborhoods, and

communities. If, after several months, attempts to secure alternative day (educational and/or vocatonal) and residential services prove unsuccessful, the possibility of modifying existing programs and services to accommodate these individuals should be given full consideration.

C. If these additional efforts prove unsuccessful the possibility of developing individual pilot programs should be examined.

(1) These pilot programs should utilize the community-based instruction strategies outlined in the last sections of this report.

(2) Professional and logistical support for these pilot programs should be requested from neighboring community colleges and universities.

(3) These pilot programs could later become established and expand to accommodate other disabled students still residing in residential schools. They could also accommodate disabled students in other educational settings including regular schools, BOCES programs and private, separate schools.

2. AN EXAMINATION SHOULD BEGIN ON STRATEGIES TO DEVELOP AND EXPAND RESIDENTIAL SERVICE SYSTEMS TO INCLUDE CHILDREN; FOR EXAMPLE THOSE INDIVIDUALS WHO MAY REQUIRE A RESIDENCE OTHER THAN THAT OF THEIR NATURAL FAMILY BUT SHOULD REMAIN IN THE LOCAL COMMUNITY. THIS WILL REQUIRE EXPANDING SOME ADULT RESIDENTIAL OPTIONS SUCH AS SUPERVISED APARTMENTS, SMALLER GROUP HOMES, RESPITE CARE, ADULT FOSTER CARE PLACEMENT, ETC., IN ADDITION TO CREATING NEW OPTIONS THESE EFFORTS WOULD COMPLIMENT THE DEVELOPMENT OF ALTERNATIVE EDUCATIONAL-VOCATIONAL PROGRAMS FOR THOSE IN RESIDENTIAL SCHOOLS.

A. Initially, the development of these residential options for children would be directed at those who might otherwise, be placed into a

residential school. These programs could expand to include others who also are in desperate need of residential programs.

3. DEVELOP POLICIES TO PROMOTE AND FACILITATE EFFECTIVE AND TIMELY TRANSITIONAL PLANNING FOR THOSE IN RESIDENTIAL SCHOOLS THROUGH JOINT AGREEMENTS BETWEEN THE DEPARTMENTS OF SOCIAL SERVICES, EDUCATION, VOCATIONAL REHABILITATION, MENTAL RETARDATION, AND MENTAL HEALTH.

   A. Transitional planning must begin in adolescence, ideally in the early teenage years. This would allow several years for securing optimum educational, vocational, and residential services for disabled adult students.

   B. The underlying goals of transitional planning should be to provide all disabled students with (1) substantial and consistent opportunities for integrated, non sheltered employment and (2) community placements which foster their full potential for independent living and interaction with their communities.

4. TRANSITIONAL CARE AND MAINTENANCE FUNDING IN ITS PRESENT FORM IS SEVERELY DISPROPORTIONATE IN ITS DIRECTIONS AND GOALS. IT REPRESENTS A LARGE APPROPRIATION OF FUNDS TARGETED TO THE SMALLEST PERCENTAGE OF THE AGING OUT POPULATION. ALONG WITH ASSISTING THOSE AGING OUT OF RESIDENTIAL SCHOOLS, CURRENT AND POTENTIAL SOURCES OF FINANCIAL AND PROGRAMMATIC ASSISTANCE NEED TO FOCUS ON THOSE AGING OUT OF PUBLIC SCHOOLS, BOCES PROGRAMS, AND OTHER PUBLIC AND PRIVATE EDUCATIONAL PROGRAMS.

   A. These efforts should be directed at providing alternatives for severely disabled individuals in educational, vocational and residential programs.

5. THERE IS A DESPERATE NEED TO EXAMINE CURRENT EDUCATIONAL, VOCATIONAL, AND RESIDENTIAL STRATEGIES FOR DISABLED PERSONS; ESPECIALLY THOSE WITH MODERATE, AND SEVERE DISABILITIES. THE PREVALENCY AND SEVERITY OF AGING OUT IN ONONDAGA COUNTY, AND INDEED ACROSS THE COUNTRY, STRONGLY SUGGESTS THAT THESE STRATEGIES ARE NOT ADEQUATELY PREPARING SEVERELY DISABLED INDIVIDUALS FOR TRANSITION AND MEANINGFUL EXISTENCES IN THE ADULT LIVING AND WORKING WORLD.

   A. This examination should utilize a comprehensive, longitudinal and definitive study of the outcomes of special education for the severely disabled residents of Onondaga County.

   B. Occurring concurrently with this study, strategies should be examined for revising current programs and services, and developing new ones which utilize integrated community-based instruction as described in the later sections of this report.

   C. This comprehensive examination of current educational, vocational, and residential strategies should represent a collective effort of the County Departments of Education, Social Services, Vocational Rehabilitation, Mental Health and Mental Retardation.

6. THE STATE OF NEW YORK MUST RECOGNIZE THAT TCM FUNDING, AND ALL OTHER EFFORTS TO ALLEVIATE THE AGING OUT CRISIS, SHOULD NOT BE LEFT OPTIONAL, BUT REFLECT A MANDATED COMMITMENT TO QUALITY EDUCATION FOR ALL OF ITS DISABLED ADULTS, REGARDLESS OF AGE OR NATURE OF DISABILITY. THIS COMMITMENT MUST BE MANIFESTED THROUGH STATE LEGISLATION, AND EFFECTIVELY TRANSLATED THROUGH PUBLIC POLICIES.

   A. The State of New York must recognize that this commitment to life-long

learning can not and should not be the unilateral fiscal or programmatic responsibility of one Department. Instead this commitment must reflect a shared and coordinated effort by the Department of Education, Social Services, Vocational Rehabilitation, Mental Health and Mental Retardation.

The research underlying this report has inevitably led to broader observations concerning the long-term causes and implications of aging out. This is why it is not only necessary to examine such pragmatic issues as the feasibility and benefit of current TCM eligibility and distribution formats; but also to recognize aging out as a symptom of problematic educational, vocational, and residential strategies. As suggested in the preface, this observation is especially critical when discussing the aging out of severely disabled invidiuals, for the strategies generated so often fail to truly develop their potential for meaningful lives and livelihoods.

For this reason, the formentioned proposals are not in and of themselves, meant to be definitive solutions to the aging out crisis. Like the development of TCM funding, they are simply a step in the right direction. They address the pragmatic concerns such as restructuring the format and distribution of TCM funding, and developing consistent and effective transitional planning for older students. But acted on alone, these efforts will only bandage and postpone the consequences of aging out. They must be accompanied by a reevaluation of current educational, vocational and residential strategies.

This effort should be undertaken in a longitudinal, comprehensive and definitive study, examining the outcomes of special education on severely disabled students in Onondaga County. This writer believes such a study would invariably lead to the promotion of the two concepts discussed towards the end of

this report: namely community-based instruction and a commitment to life-long learnings.

As we mentioned earlier, this report focuses a great deal of attention on those individuals with severe disabilities. One of the main reasons for this is the fact that those students identified in this report all have severe disabilities. And again, the severely disabled are hit particularly hard by the aging out crises. Still, there is no intent to de-emphasis or down play the problems facing mildly disabled students who age out. Those include students with learning disabilities, or a combination of disabilities. The large, more comprehensive study called for in the formentioned proposals must focus on the mildly disabled as well as those with more severe disabilities.

Before moving on, I'd like to shed more light on the intentions of this work. Its purpose is to propose ideas and directions, not indictments and indignations. At the risk of sounding patronizing, I can understand how these ideas and directions might appear more fanciful then feasible. Still, ideas and concepts are too often prematurely discounted because of striking, but superficial, complications. I would propose that before we concede to this temptation we instead courageously ask "Why not"? Certainly many parents have already done so. They have been followed by professionals, even those from agencies whose long standing policies and procedures would face drastic changes if these approaches are realized. Perhaps what follows is not without specific flaws, but neither have I discovered a definitive and compelling reason which spells its doom. Indeed, the transition of thousands from institutions to the community started with the same type of long-range, purposeful and progressive thinking.

Those who have little understanding, or perhaps are simply not moved, by the plight of the aging out might still dismiss these ideas solely because they demand a rethinking, and a determined commitment to change. So I have written

instead for those who believe that the philosophies and methodologies of special education are not carved in stone; but are always growing and changing to further serve the needs of America's disabled citizens. That this underlying commitment to the enriching of lives and livelihoods, must never be half-hearted, or grow complacent, because of partial or temporary successes. No, this report is not laced with bitter accusations; but ingrained with the belief that with our great capacity for compassion and understanding, growth and adaptability, and with the same forcefulness of spirit which spearheaded the deinsitutitional movement, we can keep moving forward. Indeed, we must keep moving forward.

INTRODUCTION

In the early months of last summer, I moved to the Syracuse area to begin work on this report. At that point, the focus and directions of my research were still very open-ended, and with good reason. For the turbulence generated by aging out has given rise to advocacy, but not substantial research . That is, this county has no exhaustive and definitive study to clearly identify the victims of aging out, or how the issue affects them individually. No numbers, charts, or timetables reflecting lost programs and services; no measures of the lost opportunities and personal disappointments. The Department of Social Services originated this report to begin defining the scope of aging out more accurately.

Obviously, this effort is critical for truly understanding the effects of aging out on its victims. But it is also critical for attempting to assess the effectiveness and future availability of "Transitional Care and Maintenance" (TCM) funding. This refers to the 1.8 million dollars appropriated by New York State to help alleviate the aging out crises. In simple terms, these monies, balanced with equal contributions from local social service departments, extend select programs and services for certain aging out victims. Yet the future of transitional funding is uncertain, since it is not mandated in part or whole through federal or state legislation. Its future could very well hinge on research reflecting the prevalence and consequences of aging out.

Given this situation, I have fashioned this study accordingly. Section One begins with an examination of transitional care and funding; what it entails and which persons and facilities are eligible to receive it. This information has been extrapolated from the pages of several memos and memorandums originating

from within and outside the Department of Social Services. It is noticeably brief, since I quickly discovered the criteria for eligibility of both participants and facilities and services is somewhat open for interpretation. A local branch of the Department of Social Services, for example, might provide for a TCM service whose funding will not be shared by the state DSS branch, such as special transportational services. This will most likely become more defined as the transitional funding process "settles into place." Also there are issues surrounding where transitional care monies should be drawn from, where additional monies will originate, etc. Though these issues are understandably important in the long run, they are not central to the purposes of this report.

The second section of this report applies the defined criteria onto those persons whose school districts lie in Onondaga County. More specifically, to those persons placed by local school districts or the Department of Social Services into residential schools (where they both reside and attend classes) who face aging out within the next three years. Since these are the only persons now eligible for transitional funds, this offers some idea of the kinds of numbers and costs which will be encountered over the next three years. Because tuition, residential and transportation costs change year to year, I am offering conservative estimates; actual costs should be assumed to be relatively higher.

The third section of this report examines aging out as the outcome of inadequate educational, vocational, and residential strategies. This is a critical issue, for without looking into <u>why</u> aging out occurs, attempts to remedy the situation instead only "band-aid" it. The points brought up discuss both short and long range issues. And while the second section focuses on identifying the needs of certain subgroups, the third section proposes ideas which could benefit the <u>entire</u> aging out population. This is a crucial distinction, for one of the inherent weaknesses of this type of preliminary study is its narrow range. There

is no direct or implied effort to draw attention away from those individuals aging out who do not presently qualify for transitional funding. Since they don't qualify, their case for exposure and attention is even more compelling. The decision to target just those in residential schools was based solely on time and personnel available. Surely the first concern of a follow-up definitive study should be the identifying of those people not targeted here.

The fourth section explores the "Community-based Alternative", which is composed of demonstrated strategies for utilizing community-based, community-oriented instruction for severely disabled individuals. These strategies have already been utilized in other states with striking results.

The fifth section examines how the community-based alternative could strengthen the effectiveness and benefit of special education in Onondaga County, and the State of New York.

The final section is simply entitled "Afterthoughts" and is just what it implies, a collection of personal, closing thoughts.

SECTION ONE

AGING OUT AND TRANSITIONAL FUNDING

A concise and clear definition of "Aging Out" appears in Developmental Disabilities Digest (May, 1984, Volume I, No. 3, page 1). It's the situation arising when mentally regarded, developmentally disabled, or youth with other handicapping conditions reach 21 years of age, and are turned out of publically funded residential, educational, and child care programs. In this context, those aging out in New York, from 1983-1988 could be anywhere from 1500-2400, depending on the specific survey utilized (Cocozza, 1983). These include students in public schools, Boards of Cooperative Educational Services, residential schools, and other special education programs. The end result of aging out for most has been an abrupt return to inadequately prepared homes and sometimes to the city streets (Developmental Digest, 1984).

In 1982 and 1983, two pieces of legislation addressing the issue were passed into law (Chapter 544 and 570 respectively). These bills provided for the planning and referral of those aging out to important adult service providers. They were the first real steps forward in the direction of aging out reforms. They were also universal in nature, in that they were directed towards the entire aging out population.

This is far from the case with Transitional Care and Maintenance (TCM) funding. It represents a considerable appropriation of money targeted to a very select aging out subgroup. Currently the 1.8 million dollars (to be matched equally with local social service departments) is solely to maintain the programs and services of those in residential schools. This has naturally infuriated those parents whose sons and daughters are aging out of public schools, and consequently receive no such relief. These students have a variety of handicaps,

including physical disabilities, various degrees of mental retardation, learning disabilities, etc.

In light of this disproportionality, there have been numerous proposals from parents and professionals to address those overlooked in TCM funding. In general terms, these include:

(1) Funding the continuance of specific educational, residential, vocational, and child care services for all individuals not presently eligible for TCM funding.

(2) Accelerating the development of community placements in Onondaga County, especially for those who require substantial assistance to live in relatively independent settings.

(3) Substantially upgrading the availability and consistency of home care services to those families in need. These support services include in home training and counseling, and respite care services.

Naturally, the last two efforts are critical to TCM recipients and non-recipients alike. But at least the former are receiving the financial support necessary to continue programs and avoid the individual and family disruptions which so often accompany aging out. And subsequently, to relieve the financial burden to the state, TCM recipients will probably receive a higher priority (along with residents awaiting departure from state institutions) for the decreasing numbers of community placement slots. Thus the situation for the individuals and families excluded from TCM funding is at best precarious, and at worst, seemingly hopeless.

That is why I have strenuously reinforced the idea that my work is a preliminary report and not a definitive study. <u>To think and react otherwise only serves to further preclude and alienate non-recipients of TCM funding</u>. This simply cannot continue! A full-scale study to identify the numbers and needs of those who have already, and will in the future, age out of non-residential programs is both necessary and urgent.

SECTION TWO

TRANSITIONAL CARE AND MAINTENANCE FUNDING TO ONONDAGA COUNTY

From this perspective, this report continues with a look at those in Onondaga County who are eligible for TCM funding during 1984, 1985, and 1986. First it is helpful to outline the eligibility criteria for TCM candidates, and chart the flow of a recipient through the TCM funding process. This will be approached in general terms to provide background information. Lengthy descriptions of programmatic and fiscal criteria are readily available from the New York State Department of Social Services. As mentioned earlier, there is some open-endedness in how these criteria are interpreted and manipulated to judge an applicants case for TCM funding. This is especially apparent in the case of those who can present a substantial and compelling case that they did not receive appropriate programs plus services until their late teens. Still, for the most part, the criteria are fairly established and clear; and are as follows:

(1) The individual must have reached the age of twenty-one within the time frame outlined by the State Department of Social Services.

(2) The individual must have a disability which falls under the auspices of the Office of Mental Retardation and Developmental Disabilities (OMRDD) which include a diagnosis of autism, cerebral palsy, epilepsy, mental retardation, neurological impairments, and any other recognized developmental disability; or the Office of Mental Health (OMH) which would include any psychiatric diagnosis such as emotional disturbance, schizophrenia, etc. In the case of a person with a dual diagnosis falling into both categories, the OMRDD would have primary responsibility.

(3) The individual must currently be living at and enrolled in a residential public or private school, and therefore not living at home. He or she must have been placed there by their local school district or the Department of Social Services. Naturally, the facility must be a properly certified and approved program.

(4) There must be no alternative placement available for the individual in his or her respective school district. This is determined by OMRDD or OMH, and to be eligible, a parent could not have refused a placement deemed appropriate by these agencies.

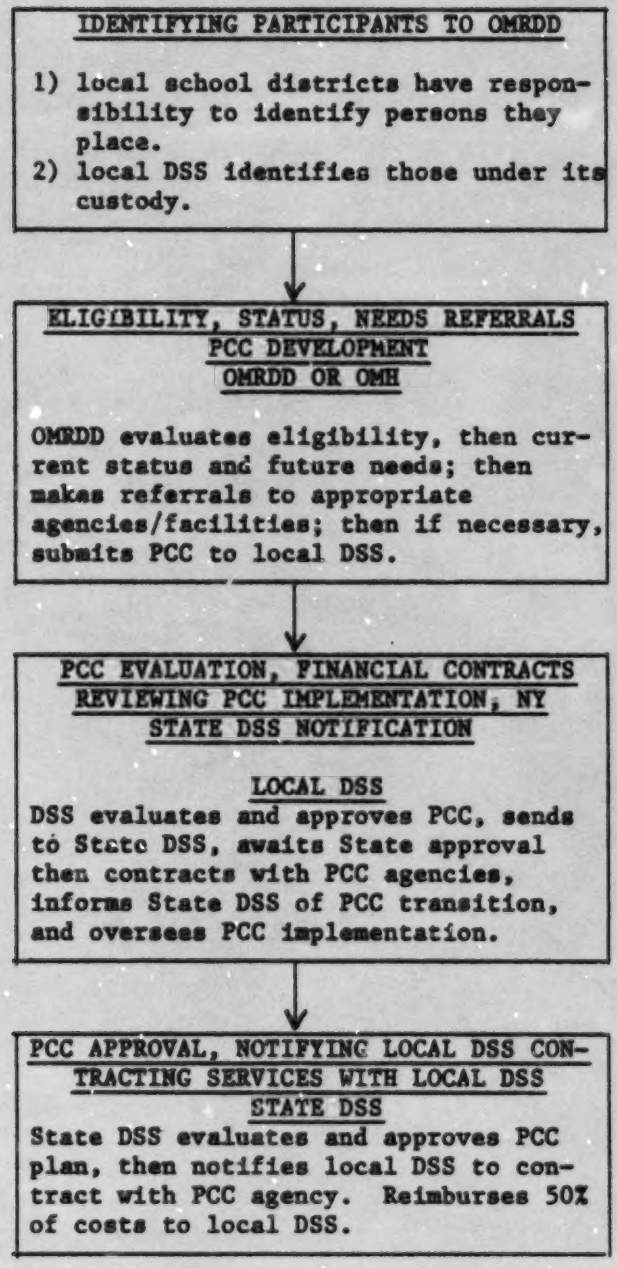
Once a person meets this criteria, he or she begins the process outlined in figure one (page 16). It begins with the mandatory identification by the local Department of Social Services or the local school districts of the persons they have placed in the above mentioned residential schools. At that point, depending on the nature of the person's disability(ies) either OMRDD or OMH begins the search for a placement considered appropriate. If a number of referrals have proved unsuccessful in securing a placement, a Plan for Continued Care (PCC) is developed by OMRDD or OMH. This plan is, in effect, a petition to the local Department of Social Services for TCM funding. In general terms, it must contain the following:

(a) A full identification of the applicant
(b) A detailed assessment of the person's current level of abilities
(c) A forecast of programs and services the person will continue to require in an alternative placement.
(d) A full accounting of efforts to place the individual outside his or her respective residential school. This includes a listing and update on every referral made, plus a description of any alternative OMRDD programs not included in the listing.
(e) A list of projected placement dates, if any, from the programs which received referrals.
(f) A review and summary of placement options.
(g) A full description of the programs and services the individual will continue to receive in his or her respective school, during the transitional funding period.
(h) Proof of an application for Social Security benefits.

When the Plan for Continued Care is completed, responsibilities begin to shift onto the local Department of Social Service branches. Each branch must fully review and evaluate individual PCCs. If a problem exists, the plan reverts back to OMRDD or OMH for reevaluation and revision. If, instead, the local Department of Social Services approves the plan, it refers it to the State Department of Social Services. That department proceeds with the same type of review and evaluation. If approved, the local Department of Social Services branch is notified and a contract is drawn between the participating residential school and the local Department of Social Services.

FIGURE ONE

THE FLOW OF TCM RESPONSIBILITY AND PROCESSES


IDENTIFYING PARTICIPANTS TO OMRDD
1) local school districts have responsibility to identify persons they place.
2) local DSS identifies those under its custody.
ELIGIBILITY, STATUS, NEEDS REFERRALS
PCC DEVELOPMENT
OMRDD OR OMH
OMRDD evaluates eligibility, then current status and future needs; then makes referrals to appropriate agencies/facilities; then if necessary, submits PCC to local DSS.
PCC EVALUATION, FINANCIAL CONTRACTS
REVIEWING PCC IMPLEMENTATION, NY STATE DSS NOTIFICATION
LOCAL DSS
DSS evaluates and approves PCC, sends to State DSS, awaits State approval then contracts with PCC agencies, informs State DSS of PCC transition, and oversees PCC implementation.
PCC APPROVAL, NOTIFYING LOCAL DSS CONTRACTING SERVICES WITH LOCAL DSS
STATE DSS
State DSS evaluates and approves PCC plan, then notifies local DSS to contract with PCC agency. Reimburses 50% of costs to local DSS.

P.C.C. Plan for Continued Care
DSS Department of Social Services
OMRDD Office of Mental Retardation and Developmental Dissabilities

With the contract drawn up, the State Department of Social Services and each of its local branches share 50% of the costs entailed in continuing the individual's program. One or more times within a ninety day period, the PCC plan is again reviewed and reevaluated by the local Department of Social Services branch. Funding is terminated upon the successful transition of the individual into an adult program. At this point the local Department of Social Services branch informs the State Department of Social Services of the transfer.

With this capsule summary layed out, this following section describes the numbers of persons who will probably petition and receive approval for transitional care and funding monies in 1984, 1985, and 1986, in Onondaga County.

SECTION TWO
THE IMPACT OF TRANSITIONAL CARE AND MAINTENANCE FUNDING TO ONONDAGA COUNTY IN 1984, 1985 and 1986

Currently, the New York State Education Department has identified 6,374 disabled, school age (5-21 years), individuals in Onondaga County.

The vast majority of these children and young adults receive their educational and vocational programming in non-residential placements; such as public schools, various BOCES branches, and separate programs run through the local Association for Retarded Citizens and the Cerebral Palsy foundation. By contrast, only 54 of these individuals have been placed in residential schools by their school districts or the Department of Social Services. This section begins by identifying the number of these residentially-based students who will reach the age of twenty-one in 1984, 1985 and 1986. All of these students could conceivably be eligible for transitional care and maintenance funding by their respective aging out dates. With this in mind, TCM cost projections for the County and State Social Service Departments are included. Finally, the individual and collective needs of these potential TCM candidates are extrapolated from current education records. This profile should facilitate the efforts of key, local adult service providers to project the availability of alternative placements and programs in this County.

The methodologies utilized in developing these number and cost projections, though time consuming, were relatively simple. The first step was contact every school district in Onondaga County and request an identification of their residentially based students who were 19, 20, and 21 years of age. For the purposes of this report, the following assumptions were then forwarded:

(1) Every student, upon reaching their aging out date, would be unsuccessful at finding an alternative placement. Subsequently, each would be seeking TCM funding to remain in their respective programs.

(2) Every student would meet the numerous criteria for TCM eligibility outlined in the previous section. These include an authenticated request for any applicable social security monies, an approved Plan for Continued Care, a documentation of referrals for alternative placements, etc.

Within this format, every student identified by the various school districts and the department of social services would then be eligible for TCM funding. The next step, then, was to develop a projection of the resulting TCM costs. The annual costs of each residential placement were determiend after contracting the Rate Setting Offices of the New York State Departments of Educaton and Social Services; both located in Albany, New York. The Baldwinsville School District provided its figures seperately.

It is important to note the general nature of these cost figures. The actual costs of TCM funding could differ depending on the number and types of services a student receives from the local DSS branch, some of which would not be funded by the state DSS. For example. certain transportational costs are not covered by the state and would have to be picked up unilaterally by the local Department of Social Services. Similarly, it is necessary to remember these costs are based on 1984 figures, and will most likely increase with each passing year. thus, all cost projections must be considered conservative. Similarly, the New York School for the Deaf, and the Rome State School for the Deaf, determine their yearly costs by dividing the total number of students into the total operating budget. Consequently, these programs have no sepearate tuition and maintenance figures, but fluctuating yearly costs. In estimating three year costs, the following formula was utilized.

(1) Each student was assumed to receive TCM funding for two years before successfully locating an alternative placement.

(2) Current 1984 costs were carried forward without consideration for possible rising costs.

(3) When students were enrolled in programs whose costs were determined by the State on a daily rate, the student was assumed to be in the program a total of 222 days (180 school days and a 6 week summer program).

The last step in identification was to target specific services which would most likely need continuation when these individuals applied for TCM funding. To avoid becoming saturated with the specific details of individual programs, only 5 major areas were identified and addressed:

(1) Educational-Vocational Services - Naturally, every student will need some form of day programming. What's important to remember is that we are talking of students whose disabilities were considered serious enough to warrant residential placement. This fact alone suggest that the search for truly effective day services could be lengthy and troublesome.

(2) Residential Services - The same potentially complications hold also for residential services. With the limited availability of community placements, those with severe disabilities are far from being guaranteed a smooth and rapid transition.

(3) Therapeutic Services - Including physical, occupational, psychological and speech therapy. The specific problems those therapies address could play a deciding role in successful placement to a community residence, and vocational program.

(4) Transportation Services - This entails any equipped vans, buses, etc., currently utilized for transporting the disabled students identified.

(5) Health Care Services - Such as special forms of nursing care, continual medical supervision, etc. This is to highlight the special needs of those severely physically involved, who might require frequent medical attention.

In reviewing student files, there was no attempt to add or delete any current services. It was assumed that whatever services the individual was currently receiving would continue to be needed. Still, it is important to consider that the nature, frequency and elimination of an individuals services often change yearly. Thus only the existence of the service is identified; no clinical descriptions or analyses are attempted. This type of indepth analysis must be attempted through a larger, more definitive study. As a preliminary

report, my goal here is to set up some general criteria for addressing the broader issues around aging out in Onondaga County.

With this in mind, the following pages identify the number of students placed in residential schools by their school districts, or the Department of Social Services, and who be eligible for TCM funding in 1984, 1985 and 1986.

THE SCHOOL DISTRICTS PARTICIPATING IN THIS STUDY

Each of the nineteen school districts in Onondaga County participated in this identification process, including:

Baldwinsville
Chittenango
East Syracuse - Minoa
Fayetteville Manlius
Jamesville - Dewitt
North Syracuse
West Genesee
Cazenovia
Fabius - Pompey
Lafayette Central
Tully Central
Westhill
Syracuse City
Lyncourt
Marcellus
Onondaga Central
Solvay
Central Square
Liverpool

Of these school districts, seven identified students placed in residential schools, who would reach 21 years of age by 1984, 1985 or 1986, including:

Baldwinsille
East Syracuse
Fayetteville Manlius
North Syracuse
West Genseee
Syracuse City
Central Square

THE RESIDENTIAL PROGRAMS TARGETED

The following residential programs were identified as current placements of potential transitional care and funding recipients.

SCHOOL AND NUMBER OF TCM CANDIDATES	STATE
Anderson School (2 students, 1 presently receiving TCM funding)	New York
Batavia School for the Blind (1)	New York
Crotchet Mountain (1)	New Hampshire
Elwyn Institute (2)	Pennsylvania
Hopevale Residential Center (1)	New York
Melmark Home (1)	Pennsylvania
New York School for the Deaf (1)	New York
Ostego School (1)	New York
Rome State School for the Deaf (1)	New York
Rhinebuck Country School (3)	New York
Woods School (1)	Pennsylvania

SUMMARY OF TRANSITIONAL CARE AND MAINTENANCE SERVICES REQUIRED IN 1984

SCHOOL DISTRICT AND NUMBER OF TCM CANDIDATES	NUMBER NEEDING CONTINUAL EDUCATIONAL AND VOCATIONAL SERVICES	NUMBER NEEDING CONTINUAL RESIDENTIAL SERVICES	NUMBER NEEDING CONTINUAL THERAPEUTIC SERVICES	NUMBER NEEDING CONTINUAL TRANSPORTATIONAL SERVICES	THOSE NEEDING CONTINUAL HEALTH CARE SERVICES
SYRACUSE - CITY (1) Student currently receiving TCM funding	1	1	1	1	0
TOTALS IN EACH SERVICE CATEGORY (1)	1	1	1	1	0

PROJECTION OF TRANSITIONAL CARE AND MAINTENANCE SERVICES REQUIRED IN 1985

SCHOOL DISTRICT AND NUMBER OF TCM CANDIDATES	NUMBER NEEDING CONTINUAL EDUCATIONAL AND VOCATIONAL SERVICES	NUMBER NEEDING CONTINUAL RESIDENTIAL SERVICES	NUMBER NEEDING CONTINUAL THERAPEUTIC SERVICES	NUMBER NEEDING CONTINUAL TRANSPORTATIONAL SERVICES	THOSE NEEDING CONTINUAL HEALTH CARE SERVICES
CENTRAL SQUARE SCHOOLS	1	1	1	1	1
EAST SYRACUSE SCHOOLS	1	1	1	1	1
FAYETTEVILLE-MANLIUS	1	1	1	1	1
NORTH SYRACUSE	1	1	1	1	0
SYRACUSE CITY	2	2	2	2	0
WEST GENESEE	2	2	2	2	0
ONONDAGA COUNTY DSS	2	2	2	0	0
TOTALS IN EACH SERVICE CATEGORY	10	10	10	8	3

PROJECTION OF TRANSITIONAL CARE AND MAINTENANCE SERVICES REQUIRED IN 1986

SCHOOL DISTRICT AND NUMBER OF TCM CANDIDATES	NUMBER NEEDING CONTINUAL EDUCATIONAL AND VOCATIONAL SERVICES	NUMBER NEEDING CONTINUAL RESIDENTIAL SERVICES	NUMBER NEEDING CONTINUAL THERAPEUTIC SERVICES	NUMBER NEEDING CONTINUAL TRANSPORTATIONAL SERVICES	THOSE NEEDING CONTINUAL HEALTH CARE SERVICES
BALDWINSVILLE SCHOOLS	1	1	1	1	1
FAYETTEVILLE-MANLIUS	2	2	2	1	1
ONONDAGA COUNTY DSS	1	1	1	0	1
TOTALS IN EACH SERVICE CATEGORY	4	4	4	2	3

SUMMARY OF TRANSITIONAL CARE AND MAINTENANCE FUNDING COSTS FOR 1984

TOTAL 1985 Costs for Onondaga County DSS 24,000

Total 1985 Costs for NY State DSS 24,000

SCHOOL DISTRICTS AND NUMBER OF TCM CANDIDATES	CURRENT ANNUAL COST OF PLACEMENT(S)	PROJECTED COST TO ONONDAGA COUNTY DSS	PROJECTED COST TO N.Y. STATE DSS
SYRACUSE CITY - STUDENT CURRENTLY RECEIVING TCM FUNDING	48,000	24,000	24,000

PROJECTION OF TRANSITIONAL CARE AND MAINTENANCE FUNDING COSTS FOR 1985

Projected 1985 Costs 322,562

= 370,562 (total cost)

Carryover costs from 1984 48,000

TOTAL 1985 Costs for Onondaga County DSS 185,281

Total 1985 Costs for State DSS 185,281

SCHOOL DISTRICTS AND NUMBER OF TCM CANDIDATES		CURRENT ANNUAL COST OF PLACEMENT(S)	PROJECTED COST TO ONONDAGA COUNTY DSS	PROJECTED COST TO N.Y. STATE DSS
CENTRAL SQUARE SCHOOLS	1	32,880	16,440	16,440
EAST SYRACUSE SCHOOLS	1	76,030	38,015	38,015
FAYETTEVILLE-MANLIUS	1	25,215	12,017	12,107
NORTH SYRACUSE	1	20,013	10,006	10,006
SYRACUSE CITY	2	63,754	31,877	31,877
WEST GENESEE	2	52,462	26,231	26,231
ONONDAGA COUNTY DSS	2	52,208	26,104	26,104

PROJECTION OF TRANSITIONAL CARE AND MAINTENANCE FUNDING COSTS FOR 1986

Projected 1986 Costs 180,884

plus

Carryover costs from 19[illegible] 322,562 = 503,446 (total cost)

plus

Carryover 1984 costs 0

TOTAL 1986 Costs for Onondaga County DSS 251,723

TOTAL 1986 Costs for State DSS 251,723

SCHOOL DISTRICTS AND NUMBER OF TCM CANDIDATES		CURRENT ANNUAL COST OF PLACEMENT(S)	PROJECTED COST TO ONONDAGA COUNTY DSS	PROJECTED COST TO N.Y. STATE DSS
BALDWINSVILLE SCHOOLS	1	52,874 (This figure supplied by the School District)	26,437	26,437
FAYETTEVILLE-MANLIUS	2	93,176	46,588	46,588
ONONDAGA COUNTY DSS	1	34,834	17,417	17,417

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SECTION THREE

THE STORY BEHIND THE AGING OUT CRISIS IN ONONDAGA COUNTY

At the earliest stage of this research, a great deal of attention was focused solely on those aging out individuals currently, or seen to be eligible for TCM funding. Naturally, the Department of Social Services initiated this report to begin defining the scope of its financial and programmatic responsibilities over the next three years. Concerns were not only expressed about the current and potential costs of continuing residentially-based programs for TCM recipients, but also about the benefit of these programs. More precisely the following questions surfaced:

(1) Have these programs truly prepared students for community placement and vocational programs?

(2) If certain students have not appeared to make significant, longitudinal progress in preparing for these goals, then how many additional years of training would be necessary? Two? Three? Five?

(3) If a great many residentially-based students needed several additional years of educational and vocational training, would TCM funding snowball into a major financial strain for the State and Local Departments of Social Services?

(4) Would long-term funding of residentially-based programs stagnate efforts towards providing new community-based residential, educational, and vocational options for TCM recipients? Would it, in effect, only serve to "band-aid" the problem?

(5) Would the subsequent channeling of increasing sums of money towards continuing residentially-based programs, lead to the exclusion of other aging out individuals from potential financial and programmatic assistance?

Again, these questions were originally raised with respect to those students attending residential schools, with the intent of examining the feasibility and benefit of long-term TCM funding. After reviewing files and discussions with various professionals, it was obvious these students were thought of as needing more comprehensive programs and services than could be offered in the more tra-

ditional public school, BOCES, etc., settings. Obviously, the goal of these residentially-based programs would be to prepare students to return to their communities with as many vocational and community living skills as possible; perhaps well before the individuals reached the age of 21 years. From that point school age individuals could return to their families, or a group home, and then utilize more standard educational and vocational programs.

I followed this logic to its final stage; namely determining the ultimate goal of educational-vocational programs for severely disabled students. Certainly the most beneficial educational and vocational programs would be characterized by a high percentage of severely disabled individuals finding meaningful roles in the community and the work force. Programs less beneficial would see more of their students ending up in highly dependent environments seperated from the mainstream of the community. Similarly, the most beneficial programs would not only assist individuals to be more socially and vocationally independent, but more financially independent. Conversely, less beneficial programs would likely be characterized by individuals requiring extremely costly programs while contributing little if anything back to the community, state, or federal government. Of course, I'm not suggesting that the value of individuals be judged solely on their financial contribution to society, but efforts towards independence are undeniably ingrained in the American Work and social ethic.

With this format in mind, it soon became strikingly clear that the most successful educational-vocational programs for severely mentally and physically disabled individuals were community-based and community oriented. That is, through individualized, community-based vocational training, and intensive community living skills (as opposed to purely academic) programs, high numbers of individuals who would routinely end up in sheltered work shops and day treatment facilities, instead secured competitive work and more independent lifestyles.

(Brown, et al., 1983a; Hill and Wehman, 1982; Wehman, et al., 1982). Their success also reflected considerable savings to taxpayers when compared to substantial costs for long-term care in sheltered work shops, day treatment, institutions and other highly dependent, segregated environments (Brown, et al., 1983a; Hill and Wehman, 1982; Schneider, Rusch, Henderson, Geske, 1981; Wehman et al., 1982).

The startling success of community-based programs inevitably revealed some inherent weaknesses of residentially based programs. More than that, it reflected the disadvantages of all segregated educational, vocational and residential programs serving severely disabled persons. This is the true story behind the aging out crises in Onondaga County, in New York State, and indeed across the United States. The aging out crisis reflects more than any thing else, the underlying deficiencies in the way special education prepares, or more accurately, doesn't prepare, severely mentally and physically disabled students for relatively independent living and working.

It is not simply an issue of changing curriculums to reflect community-living and non-sheltered vocational areas. Just as the structure, size, and segregated nature of institutions condemn the efforts of the most inspired administrators and personnel, (Blatt, 1981; Blatt, Ozolins, and McNally, 1979) residential schools also have inherent weaknesses, mainly in their potential to develop to the same degree, those skills of their community-based counterparts. Even the most well-intentioned, sophisticated and endowed residential schools, cannot provide educational-vocational programs in the same environment the student is eventually returning to. Thus, their graduates, including those with the most sophisticated community living and vocational skills must return to a community which may be foreign and frightening. Unless they are very fortunate, they also leave behind well established relationships with teachers and other

other students, only to find themselves strangers in their communities, and sometimes in their own families.

Finally, residential programs generally entail substantially more costs than their community-based counter parts. For example, there are no "overhead" costs for bringing a student to their community grocery store to learn vocational skills. But when a residential school designs and constructs a "simulated" grocery store environment, it entails buying an array of shelves, push carts, refrigeration units, cash registers, etc. The process has to be repeated for other simulated environment, and the subsequent costs would inevitably be reflected in increased tuition and maintenance costs. While the Department of Education might be supporting this type of program early on, the responsibility will fall onto the Department of Social Services if its students eventually need TCM funding. And what about the student? When all this simulated training, in simulated worksights, utilizing simulated supervisors and co-workers, organized according to simulated work-days is finished, where does the student find employment? Not with a community employer who doesn't know, and might not care to know, the student; but more likely in a sheltered workshop performing non-meaningful work for sub-minimum wages. In essence, all the years of educational training and financial support have meant little to the state, the taxpayers and most importantly the severely disabled individual.

That is why this report must begin to examine the community-based, community-oriented alternative. Once the nature, structure and goals of these programs are clearly revealed, they go far beyond undermining the strategies of placing, or continuing the programs of students in out-of-district residential schools. More than that, they offer a compelling argument against educating <u>any</u> severely disabled person in <u>any</u> separate, segregated environment, especially if the program doesn't utilize home communities for developing independent living and

vocational skills. This preliminary report can only begin to address the question of the long term effectiveness and benefit of current educational strategies for those with severe disabilities. Previously, the need for a definitive longitudinal study was emphasized. Along with a full identification of all those aging out of publicly supported programs, and services, this future study must address this very fundamental and vitally important question.

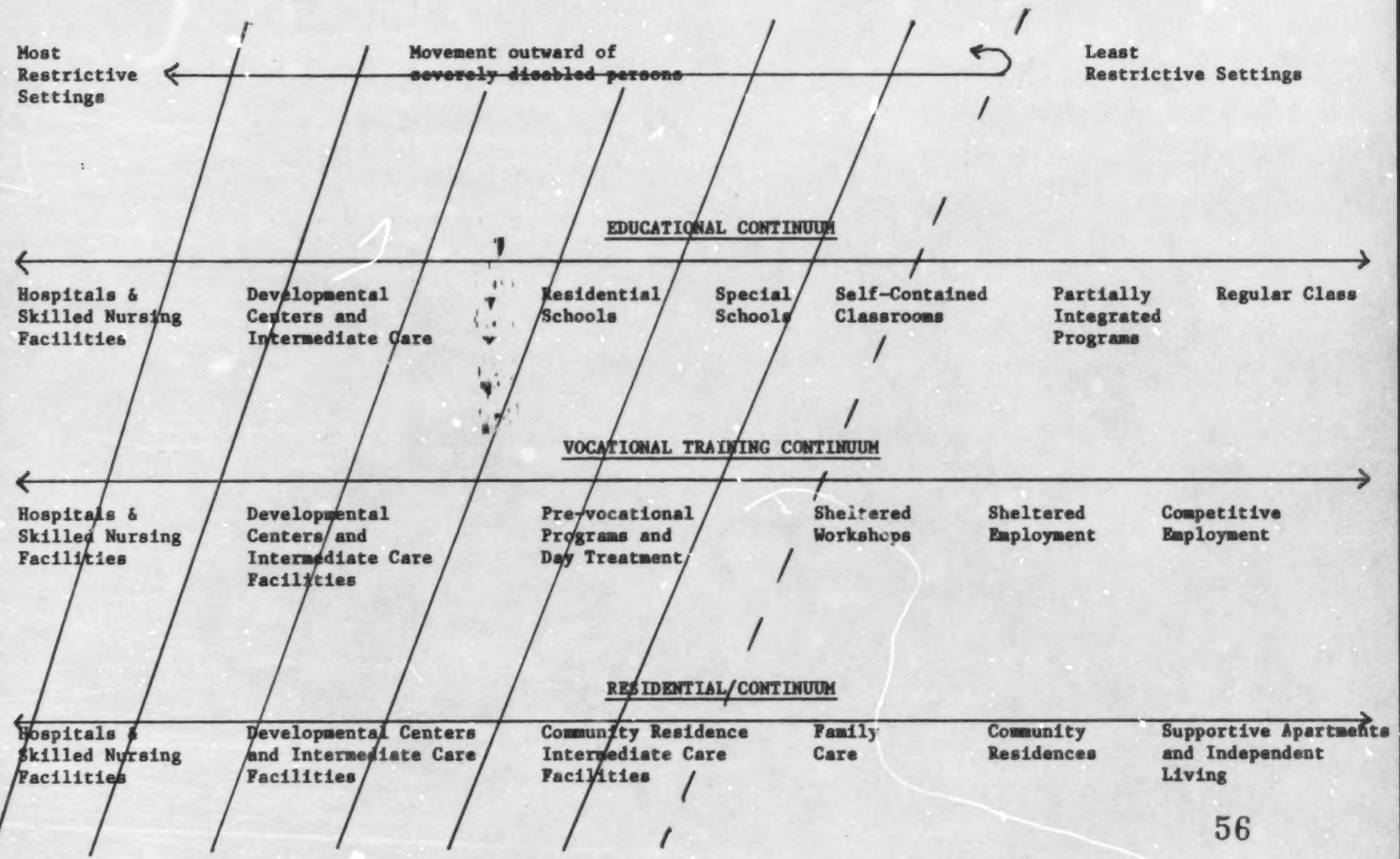
. . . . . .

In order to fully appreciate community-based alternative educational and vocational programs, it is necessary to examine the nature and outcome of current non-community strategies. Special education in Onondaga County as well as most of the country, is best described as three distinct but interrelated continuums (see figure 2). Each continuum represents a spectrum of environments and programs in education, vocational training and residential services. (OMRDD, 1984; Hamre-Nietupski, Nietupski, Stainback and Stainback, 1984). Moving from left to right, persons are seen progressing through each continuum from generally more restrictive to generally less restrictive environments. That is, individuals traditionally move from more restrictive settings, such as institutional placements, to less restrictive community homes. In the same manner, individuals move from move restrictive day treatment programs to regular classrooms. The vocational training continuum sees students move from more restrictive day treatment programs to competitive work environments. In reality, the term "movement" is somewhat figurative in that many individuals are placed into less restrictive environments without having to experience more restrictive ones. The point is that wherever an individual begins on a particular continuum, educational, vocational and residential training strategies are utilized to move the person to the least restrictive environment within the continuum. The ultimate goal of this outward movement is to nurture maximum personal and financial independence in living and working environments.

Yet, as was previously stated, these continuums have significant meaning for individuals with severe disabilities. For a majority of these individuals, significant outward movement within each continuum is difficult if not nearly impossible. As demonstrated in figure 2, these individuals often become "stuck" in the cross-meshed area representing more restrictive educational, vocational

FIGURE TWO

CONTINUUMS GOVERNING EDUCATIONAL, VOCATIONAL AND RESIDENTIAL PLACEMENTS FOR DISABLED PERSONS



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and residential environments. It is helpful to examine the nature and strategies of these continuums and environments.

THE EDUCATIONAL CONTINUUM

Within the educational continuum, many mildly disabled individuals reach the public schools within regular and self-contained classrooms. Many severely disabled individuals however are placed in more restrictive settings including separate, segregated schools. These include institutional programs, residential schools, BOCES schools and privately sponsored schools such as that founded by the Association for Retarded Citizens. While the individual characteristics of segregated programs differ, they generally utilize the following strategies:

(1) Homogeneous groupings: Residential schools, BOCES programs and other segregated schools often group students according to the nature of their disability(s) and their level of academic functioning. Thus, a separate school might have a class for persons labeled emotionally disturbed, another for individuals with severe physical disabilities, and still another for students blind and deaf. Brown (1976) realizing that regular education somewhat utilizes this "logic of homogeneity", still makes a compelling case for the deficiencies of this strategy. He concludes that "educators have systematically, although inadvertently, impeded many handicapped and non-handicapped students from acquiring the skills, values, and attitudes necessary to function in heterogeneous multifaceted and interpersonally complex adult environments. (Brown, L., Nietupski, J., Hamre-Nietupski, S. 1976. The Criterion of Ultimate Function. In M. Thomas (ed.). Hey, don't forget about me! Educations investment in the severely and profoundly handi-

capped. Reston, VA: The Council for Exceptional Children.) Dr. Brown's discontent with this strategy has received growing support in the special education literature (McHale and Simeonsson, 1980, Stainback and Stainback, 1981; Voeltz, 1980). There are many more studies, and what their authors are stressing is simple but so very important: grouping severely disabled students in this fashion generates far more problems than it solves. Some of these problems are briefly outlined below:

(a) Homogeneous grouping denies disabled individuals and their non-disabled peers crucial social contacts with one another. In residential schools this is even more apparent, because students do not have the opportunity to return to their community and home to be with non-disabled parents, siblings, friends, etc. The interaction these residential students have with non-disabled persons is usually centered around teachers, administrators and other school staff.

(b) Homogeneous grouping can itself actually contribute to lack of motivation and higher degrees of disruption in classrooms. The forementioned studies stress that when disabled persons work and play alongside non-disabled peers, those non-disabled students can become very effective and positive role models for their disabled counterparts. In many cases, expectations for skill learning increases as well as expectations for appropriate social behaviors. Whereas in separate segregated environments, student expectations can be dampened and inappropriate behaviors generated. In an environment containing several students with severe behavioral problems, it is often the case that each student's inappropriate behavior triggers off others. This can continue to the point where behavior management takes precedent over teaching skills. This author's experiences teaching in a residential school over a two year period strongly support this observation.

(c) Homogenous groupings can act to lower teacher expectations of their students. When a teacher is in contact only with students having severe behavioral problems and/or physical disabilities it can become quite difficult to vision these students interacting and growing in community settings with non-disabled peers. This can directly reflect on a teacher's expectations for students developing the skills integral to this goal.

(2) <u>Developmentally based instruction:</u> This refers to the traditional approaches ingrained in teaching academic skills. In simple terms,

developmentally based instruction entails learning small "sub-skills" before attempting to learn a larger, more complex skill. For example, a student learns to read small sentences before reading lengthy paragraphs. While this approach is often appropriate for teaching non-disabled or mildly disabled students, it accomplishes little for severely disabled individuals. The reason is that developmentally based instruction is molded around the learning and development stages of non-disabled children. Non-disabled children learn quite well through developing sub-skills and transferring them to more complex and broader skills.

With severely disabled individuals, though, this developmental learning process simply doesn't apply. These students not only have difficulty acquiring many of these smaller skills, they can have even greater difficulty transferring these skills to the larger goal being addressed. Thus a student in a residential school might after several years be able to recognize 3 or 4 numbers, but will not be able to utilize this skill to perform simple calculations. When taken across the board, these students might learn sub-skills in many areas but end up gaining few if any major skills. For students with severe physical disabilities inhibiting both movement and communication, the failure to pick up most sub-skills leads to few if any noticeable gains even as the person reaches adulthood. Consequently these individuals often end up in adult "day treatment" programs which are highly custodial in nature, instead of more independent alternatives. Even those who develop many more sub-skills do not acquire enough significant gains.

The result in both cases is a great amount of time and effort contributed towards the development of few if any significant skills.

(3) Pre-academic and Pre-vocational skill training: Along with relying on the teaching of sub-skills to develop major skills, those skills are often pre-academic and pre-vocational in nature. For example, severely disabled individuals spend a great amount of time learning reading and writing pre-skills. Yet, the skills don't necessarily lead to independent living skills such as crossing streets, buying a newspaper, etc. In the same manner, learning how to sort screws doesn't mean a person will be able to assemble or work in a grocery store. In essence, these strategies do not prepare students for independent environments such as community residences and meaningful work. Instead, it almost inevitably leads severely disabled individuals into day treatment programs or sheltered workshops. It has now been strongly demonstrated that it is far more effective and beneficial to provide age appropriate instruction directed towards developing independent living and working skills, (Brown et al., 1976; Baumgart et al., 1982; Ford, Johnson, Pumpian, Stengert, Wheeler, 1980), instead of, for example, having a 17 year old student working months on assembling a 5 piece puzzle of Donald Duck.

(4) School based Instruction: In residential schools and other separate schools, most instruction takes place on school grounds and not within the community. Even when community-oriented skills are addressed, such as bus riding, it often takes place in a simulated environment. For example, schools might actually make a cardboard "bus" to simulate bus riding. Pre-vocational training might use simulated assembly lines as compared to a real assembly line within a community factory.

These simulated environments might help to some degree in gaining select skills, but it is much more advantageous to develop community skills in those environments the individual will be utilizing. (Brown et al., 1976; Baumgart et al., 1982). Because severely disabled individuals can be expected to learn little through developmentally-based, pre-academic and pre-vocational instruction (Brown et al., 1983c) it seems imminently practical and advantageous to provide considerable instruction outside of the schools (Brown et al., 1983c Brown et, Baumgart et al., 1982). As we shall see, the community based alternative offers many exciting strategies to address these weaknesses in the educational continuum.

THE VOCATIONAL TRAINING CONTINUUM

Just as with the educational continuum, traditional vocational training strategies, though well intentioned, have fallen short of providing truly meaningful opportunities for employment. And for many of the same reasons, some of which are outlined below:

(1) Homogenous groupings: For the most part vocational training for severely disabled persons takes place in homogenous groups with few if any non-disabled students. This not only occurs with in-school vocational training (in classrooms or simulated workshops) but also in adult sheltered workshops. For example, a sheltered workshop might be composed of 40 or 50 disabled workers and a dozen or so staff persons. Just as in homogeneous classrooms, this environment can in and of itself encourage a great number of inappropriate behaviors. (Brown et al., 1983; Wehman, p., 1983). One important reason for this is the

lack of non-disabled workers to serve as positive role models. Staff may serve this function to some degree, but they are not usually working alongside a severely disabled worker. Thus they may be modeling appropriate observing behavior, but not appropriate working behaviors. Another contributing factor is the tendency for supervisors, staff and co-workers in sheltered workshops and other homogenous work environments to overlook or accept inappropriate behaviors which would bring social repercussions in normal work settings (Brown et al., 1983 b, Wehman, p. 1983). This can be attributed to the fact that homogenous work environments are in essence simulated, unreal settings. And it is very difficult to have realistic and normal expectations of work and social behaviors in settings which are neither realistic nor normal. Yet without these normal consequences and reactions, individuals, especially those with moderate or severe behavior problems, have little to guide their behaviors. (Brown et al., 1983 b).

(2) Developmentally based pre-vocational instruction: Just as its educational counterpart, traditional vocational training strategies rely on non-realistic learning processes and goals. (Brown et al., 1983 b; Wehman 1982). That is, severely disabled persons are expected to learn vocational skills in the same way as their non-disabled peers. They are exposed to a variety of pre-vocational sub-skills (such as putting pegs into a board) with the hope of developing related complex and refined skills (such as assembling electrical components). Yet as with pre-academic training, many severely disabled persons spend several valuable years learning a small number of sub-skills only to find themselves unable to transfer them to more meaningful tasks.

Consequently, even after several years of pre-vocational training, the only vocational setting for these individuals is a sheltered workshop. Those who develop few if any of these sub-skills cannot even qualify for entrance into a workshop and instead spend their adulthood in social day care, day activity centers and other often very dependent, restrictive environments. (Brown et al., 1983 b).

(3) School and/or Workshop-based instruction: Even those individuals with relatively high levels of pre-vocational skills, often find themselves receiving additional training solely in classes, workshops and other non-community settings. Again, this strategy is based on the assumption that whatever vocational skills are developed in sheltered environments will be transferable to community employment sites. This is simply not the case. At the risk of sounding redundant, it must be reemphasized that it is not possible to replicate all the individual and critically important features of a grocery store, assembly line, auto service station, etc., in a sheltered environment. (Brown et al., 1983 b; 1983 c). Not only do traditional sheltered strategies fail to expose students to realistic environments, they do not offer disabled students valuable work and social interactions with non-disabled employers and co-workers. Thus students do not have the opportunity to develop relationships with potential employers; relationships which could strongly influence the hiring of a person despite noticeable physical and emotional problems. Also sheltered environments do little to develop the transportational and related community skills essential to getting to and from work. Many sheltered workshops instead utilize subsidized transportation such as special buses, etc. In residential

schools there is often even fewer opportunities to develop these skills, because many workshops are situated within or adjacent to the school building(s).

(4) Delayed vocation training: Generally vocational training for non-disabled and severely disabled persons begins as they approach adulthood. Yet these are important reasons why vocational training should begin much, much earlier for severely disabled students. First, these individuals need a great deal more time to develop even the simpler vocational skills necessary for non-sheltered employment. (Brown et at., 1983 b). Secondly, by their teenage years, most non-disabled individuals already have some experiences performing work and earning money. They have mowed lawns, babysat for friends and relatives, delivered papers, and perhaps have been employed in family run businesses. Similarly, they might have already opened bank accounts and otherwise become familiar with managing weekly allowances or pay. Those with severe disabilities, often do not have the same degree of experience. This is likely to be even more true for those in residential schools, who have less contact with family and therefore less opportunities to do simple jobs around the house or yard.

There are other problems with traditional vocational training strategies; all strongly support the alternative strategy that the most beneficial and effective vocational training for severely disabled persons utilizes potential employment sites within the community along with the actual tasks and goals necessary to be successful within that

particular worksite. If you want to most effectively train a disabled person in custodial skills, then, he or she should learn how to sweep floors, empty baskets and related tasks in one or more custodial worksites within the community. In the long run, community based instruction is also less costly in terms of training costs and eventual taxpayer savings as compared to costly sheltered environments (Brown et al., 1983b; Hamre-Nietupski, Nietupski, Bates and Maurer, 1982).

RESIDENTIAL SERVICES CONTINUUM

The residential continuum is very much effected by the educational and vocational training curriculums. For as students acquire more sophisticated community living skills and vocational skills, they naturally become potential candidates for more independent residential services. Yet there are more important problems facing those agencies, such as Seguin Community Services, who help develop residential programs. With the decreasing number of community placements there is increasing competition for them from (1) students in residential schools, (2) adults in larger state facilities such as developmental centers, and (3) those adults who were living at home but for one or more reasons need alternative living arrangements. At the same time there are limited community living options for young children who otherwise would be candidates for placement in residential schools. This is especially important, because effective, community based educational and vocational training programs can't be utilized if there are no places in the community for these students to live.

There is also a great need to further develop financial and personal programs to assist families who keep their severely disabled children at home. If these services are strengthened, it could lead to fewer students being placed in

residential schools because families are not prepared or equipped to have them home. Of course, these services would also assist the many families whose severely disabled members attend regular or separate schools and who are not currently eligible for TCM funding.

There are many more financial and legal considerations that effect the development and availability of community placements, more than can be substantially addressed in this preliminary report. However one issue concerning community living options is very much related to educational and vocational training. This is the area of society's acceptance and relationship with the severely disabled. One of the major problems facing agencies such as Seguin Community Services is the public's fear of community homes. Fears of reduced property values; and fears of disabled individuals in general. The only way to allay these fears is to nurture relationships between a community and its disabled citizens. Just as non-disabled and disabled children alike benefited from exposure and interaction with one another, (Brown et al, 1983; Stainback and Stainback, 1981) there is no reason to believe otherwise with regard to adults. But this can't occur if we continue to separate severely disabled persons from their community by placing them in residential schools, separate schools, sheltered workshops and even self-contained classes substantially apart from regular school classes. No matter what attractive labels are placed on segregated programs and policies, they remain segregated. And segregation so often leads to isolation and alienation; in essence betraying the noble intentions we so often attribute to special education.

This is why this report has digressed away from solely examining the situation of those in residential schools. The problems highlighted by these studies, and in discussions with many professionals and some parents, have left this writer with the overpowering belief that present educational and vocational

strategies <u>for all severely disabled persons</u> must be examined and possibly restructured. This will involve joint efforts of all the traditional human-service and educational departments and agencies on both the local and state level. This report has surfaced these ideas, but it remains up to those with pivotal roles in the special education-human service systems to make them real. It might not be a simple process, or one which can be rapidly implemented, but it is a process which must begin if we are to keep the promises special education makes; namely to help realize the potential of every disabled person. To help disabled persons overcome, with spirit, strength and compassion, what barriers stand in their way. To abandon this goal for any individual or group because of their age or the nature of their disability(s) betrays and indignifies us all.

SECTION FOUR

THE COMMUNITY-BASED, COMMUNITY-ORIENTED ALTERNATIVE

What are we to do then, with those in residential schools? And how will alternative strategies address the needs of those in other non-intergrated educational and vocational programs? The answer has many distinct yet interrelated answers, weaved together nicely in the community-based, community-oriented alternative. Again, the goal of this alternative approach is to utilize integrated community settings and appropriate, functional, educational-vocational strategies to develop the highest potential for independent community living and working. The strategies presented are far from new; Their utilization and benefit have successfully stood the test of time (Brown et al., 1981; 1983b). A brief examination of the community-based alternative follows.

The community based alternative begins with a look into the future. More specifically it begins with the vision of the future we have for severely disabled persons. As was stated in the preface, the lives of these individuals can be thought of as a story which we can help write. Here is the type of ending community based proponents would like to write:

> "Thousands of severely handicapped citizens will attend church, shop, wait in the offices of physicians, ride public buses, wash dishes, attend movies, use restrooms, cross streets and cheer at football games with less handicapped and non handicapped citizens. (Brown, Nietupski, Hamre-Nietupski, 1976, p. 8).

The authors of this quote had this vision of a new future for severely disabled persons almost nine years ago. Naturally, they were not sure at that time how many of the particular goals would be realized by each severely disabled individual. But they still designed strategies to reach those goals utilizing what they termed "The Criterion of Ultimate Functioning". They thought about all the normal activities non-disabled persons engage in, and considered them the

"ultimate criterion" for determining what should be taught and how. For example, living in the city entails foremost utilizing public transportation. Thus, this became one goal of teaching. In the same manner, seeing movies, buying weekly groceries, washing clothes, etc. all became educational goals. While traditional pre-academic skills might contribute somewhat to pursuing these activities, they were not considered a prerequisite to learning the activity. Instead, persons were instructed over long periods of time how to use buses, see movies, etc. They were not taught this in the confines of a classroom but in the particular environments where these activities would take place. No simulated buses, mailboxes, etc. were used. Instead, natural, perfectly accurate, and already existing (and therefore no-cost) buses, mailboxes, check-out counters, etc., were used. The result? Many persons who demonstrated few pre-academic skills were still capable of performing the activities supposedly dependent on those skills. From there, attention was turned to vocational training. Instead of providing training in segregated, sheltered environments, community worksites were utilized. The same results developed; students who formally would have been considered destined for sheltered work or day activity programs instead found meaningful work and competitive pay. (Brown et at., 1983 b).

Community based education has now been utilized in several states including Wisconsin, (Brown et at., 1983b;) Illinois, (Fregon et al., 1983) and Iowa (Hamre-Nietupski, Nietupski, Bates,and Maurer, 1982). This report will not go into depth on the nature of these educational programs. An abundance of research examining specific methodologies and the subsequent benefits of community based training have already been referred throughout this work. But it is helpful to examine the key features underlying community based programming:

(1) Community based teaching directs itself toward the goal of having

severely disabled individuals participate as fully as possible in their respective communities and in meaningful non-sheltered work.

(2) Community based instruction insists that all teaching occurring in and out of the classroom be relevant and functional with respect to the community living and working goals a student has. Thus students do not work on tasks which are not age-inappropriate tasks such as putting animal puzzles together, when those skills aren't necessary for gaining employment, dressing, cooking, and otherwise living independently in the community.

(3) Community based teaching utilizes <u>fully integrated</u> settings to derive all the benefits possible when disabled and non-disabled persons live, learn and grow together.

(4) Community based teaching utilizes living, recreational, and vocational environments existing naturally within each respective community to develop the skills advantageous for fully functioning in that environment. Bus riding skills are developed on public transportation, vocational skills are developed in restaurants, cafeterias and other functional worksites, etc. Independent living skills are taught in community residences, actual student homes and other natural environments. Community survival skills such as crossing streets are developed at local intersections, bus stops, etc.

(5) Community based teaching is developed through continual personal contact with parents and families. The various skills developed are ones directly applicable to the students natural home and surrounding streets, playgrounds, stores, restaurants, etc.

(6) Community based instruction doesn't rely solely on artificial prompts

and cues, but instead utilizes natural cues in the community and natural reactions and responses to student behaviors.

(7) Community based instruction is not episodic, (happening once or twice a week) but longitudinal. Community living and non-sheltered employment skills are addressed as early as possible and always with the idea of transitioning students smoothly and effectively from school environments to the adult living and work settings.

SECTION FIVE

ADDRESS THE AGING OUT CRISES IN ONONDAGA COUNTY THROUGH THE COMMUNITY-BASED ALTERNATIVE

This report hopefully has demonstrated the clear, long-term benefits to using community based educational and vocational strategies with severely disabled individuals. But how can these strategies be utilized to address the current aging-out situation in Onondaga County? The "Transitional Care and Maintenance Funding Proposals" outlined earlier provide an important first step. They serve as a starting point for the much more comprehensive efforts which must begin if we are to address aging out now, and seriously curtail its continuance in the future. This section examines both short term and long term strategies in this direction.

THE COMMITMENT TO LIFE LONG LEARNING

Before any short and long term strategies are presented, it is necessary to examine where they will be derived from. Presently, the State of New York has offered its only strategy directed at aging out, transitional care and maintenance funding, as an optional program for each county's Department of Social Services.

The Onondaga Department of Social Services has taken an active interest in utilizing those funds, along with its own monies, to provide assistance in this area. Other county DSS branches have shown the same interest. But it is important to remember that few eligible TCM funding participants have been identified. This is primarily due to the narrow focus of this assistance. As has already

been stated, there is a growing movement to expand current aging out monies, to include those aging out of regular public schools, BOCES schools, etc.

Naturally, this expansion would mean the identification of large numbers of eligible applicants for programs and services. It is safe to speculate that the cost of providing aging out assistance will rise as a consequence of this growing population. But is it safe to assume the county branches of the Department of Social Services will be willing to voluntarily and exclusively contribute larger and larger sums of money in this direction. This writer cannot help but think not, and neither does it seem financially or programmatically reasonable to expect such a unilateral effort. That is why efforts towards aging out should not be optional, but instead be a reflection of New York State's commitment to life-long learning. And that this commitment be manifested through state legislation, and eventually through federal legislation.

Why a commitment to life-long learning? Perhaps the most important reasons center on society's responsibility to its disabled citizens. Providing quality education for severely disabled persons is already a commitment manifested and mandated in Federal and State legislation. At the forefront of this commitment lies the Education for All Handicapped Children Act of 1975 (PL92-142). Yet as this report stressed earlier, this law in and of itself means little if the goals it embodies are not ingrained public policies. More than that, the administration and implementation of those policies cannot be considered complete until they bring about what the law envisions. This report has presented the equipment that in this context, our educational and vocational strategies have not truly envisioned or realized the goals of PL94-142. They have not led to the development of the full potential of severely disabled persons. They have not prepared the majority of severely disabled individuals for relatively independent

lifestyles and meaningful work. Instead, it has directly and in many cases inadvertently fostered dependence and obscurity.

We must now recognize that the abandonment of meaningful education for severely disabled individuals on the basis of age, when their education is neither complete nor consumate, amounts to an abandonment of The Law. Maybe not of the letter of the law, but an abandonment of the spirit of the Law. We must continue our commitment to the education of our citizens, including severely disabled citizens, until the goals of their education are realized. This doesn't translate into filling our public school classrooms with severely disabled adults. Instead, our commitment to the meaningful education of severely disabled adults must take place in the community. It must take place on the streets, in stores, restaurants, arcades, newspaper stands, sports stadiums, libraries, churches, hospitals, dentists, offices, and in the home. It must provide severely disabled persons with the tool they need to be an active member of their community, and it must nurture and foster their growth, confidence and self-worth. While "Life Long learning" suggests long term education, in reality the educational benefits of community based education will certainly be derived by many individuals before or soon after they turn 21 years of age, especially if these strategies are utilized at the beginning of the educational process. For others, the commitment may involve more long-term educational and vocational strategies.

This commitment to the education of severely disabled adults cannot and should not be a unilateral effort or responsibility of one Department. Both the financial and programmatic responsibility for this education should be distributed among the education, social services, and mental hygiene systems. Just as each has a role in the growth and development of severely disabled children, each has a responsibility towards severely disabled adults.

The commitment to life long learning is not grounded simply in ethical convictions, but also in financial effectiveness. Individually and collectively, these departments expend considerable revenues towards the development and expansion of segregated, highly dependent educational and vocational environments. Along with the questionable effectiveness and benefit of these programs they are enormously cost-inefficient (Brown et al., 1982). More, than not, the segregated, highly dependent adult environments they lead many severely disabled students to are also enormously cost-inefficient (brown et al., 1982). Community based programming, even when it initially requires new expenditures for developing programs and personnel, is more cost-effective and beneficial for severely disabled individuals. (Brown et al., 1983b; 1983c; Hemre-Bietupski, Nietupski, Bates and Maurer, 1982;). In the long run, the benefit of community based programs is reflected in savings to service providers and taxpayers.

When discussing the idea of a commitment to Life Long Learning, many will insist the Department of Education historically has no financial and programmatic responsibility for the education of severely disabled adults. That may be true to some degree, but there exists a clear precedent which suggests otherwise. Today, in every state, we can see the critical role the Department of Education plays in adult education. Virtually every post-secondary educational institution, and other form of adult education, draws financial and programmatic resources and support from their respective State Department of Education. Vast and almost limitless opportunities for educational advancement and personal growth for America's adults have resulted from this commitment. Why shouldn't the same opportunities for education and personal growth be available for disabled individuals who desperately need assistance? Certainly the importance of an academic course for a college student is matched by the benefits of teaching a severely disabled person to perform meaningful work. With this in

mind, private and public post-secondary institutions for learning provide a richly fertile environment for ideas, personal, and other resources from which to develop community based strategies.

SHORT TERM COMMUNITY BASED STRATEGIES

Short term strategies for addressing the aging out crisis in Onondaga County natu ally begin with Transitional Care and Maintenance Funding. This funding should be utilized to continue the current placements of students in residential school, but only as an interim measure. During TCM funding, strategies to return these students should be developed and examined. While this report has exposed some inherent weaknesses in segregated, separate educational and vocational programs in Onondaga County, obviously these programs are not going to be swiftly abandoned. But we can abandon many of the strategies these programs encompass by modifying their programs to foster community based alternative strategies. The United Cerebral Palsy Center is already undertaking this vital effort by developing novel educational programs for some of its clients. Surely, it is reasonable to expect BOCES schools, the ARC school and other separate programs to begin their own reevaluation. With careful and effective planning, these programs could as a short-term answer to community based learning. Perhaps students could be returned from residential schools much earlier than planned to utilize these programs.

While alternative educational-vocational strategies are examined, the critical area of residential services should be addressed. A determined effort must continue to provide less restrictive community placements for severely disabled persons. Resources should be directed at developing new and more independent living options for moderately and severely disabled adults. Community living options for younger children who otherwise might require a residential

school should continue to be developed. And financial and personnel assistance for parents and families with severely disabled members should be continually expanded so they can continue to live and grow within their own families, homes, and neighborhoods. Every source of financial assistance must be utilized to develop community based residential programs. This will entail reevaluating current funding mechanisms with the human service systems (i.e., medicaid, etc.)

This leads to the next issue, namely redirecting the current direction of aging out funding. As alternative programs and services are developed for individuals currently served in residential schools, hopefully fewer persons will require TCM funding. As this occurs, new strategies for re-channeling that money to assist the remaining aging out population should be considered. As suggested earlier, the State Departments of Education, Vocational Rehabilitation, Mental Hygiene and Mental Retardation should be elected to contribute monies in this direction.

LONE TERM COMMUNITY BASED STRATEGIES

The short term proposals offered provide a solid base for long term aging out reforms. Collectively they address the pragmatic concerns and issues around individuals currently or soon to be, aging out.

Long term reforms must stem from the perspective of aging out as a symptom of inadequate educational, vocational, and residential strategies. Within that context, comprehensive, integrated community based instruction must be integral in the education of severely disabled individuals.

This would include the following strategies:

(1) An effective and beneficial mixture of community skill training in school, in the community, and in students homes.

(2) Vocational strategies would be ingrained in the very beginning of the educational process. As a student reaches his/her early, mid, and late

teenage years, more and more vocational training would occur outside the school.

(3) All in-school educational and vocational training, would take place within integrated classes within regular schools, within each person's school district.

(4) All school based and community based instruction would be functional, relevant, age-appropriate and developed in conjunction with input from parents, families, perspective employers, etc.

(5) Transitional planning would be longitudinal; beginning at the early teenage years and extending into adulthood. It would be characterized by joint effort and agreements between all key child and adult service providers, and not left to the auspices of one department or agency.

(6) Residential services would be continually developed to meet the needs of all severely disabled persons, including those with severe physical and/or behavior disabilities.

(7) Nearby universities, colleges, and other institutions of learning would be encouraged to contribute to the planning, development and implimentation of community based instruction and non-sheltered vocational training. Professionals, and students in various human service and educational fields of study would be utilized, as well as school buildings and grounds.

(8) Intensive efforts would continue to foster public awareness and understanding of the abilities and potential of severely disabled individuals. Public meetings would be held examining the benefit and effectiveness of community based training through films, sideshows, and other presentations.

(9) Every effort will be expended to channel and rechannel the flow of various monies targeted at special education, rehabilitation, etc. towards community based alternative programs.

(10) Eventually, all non-integrated educational and vocational training programs will be phased out, to be replaced by these integrated, community based models.

(11) Residential services will also strive to more fully integrate disabled and non-disabled individuals in group homes and other residences. Severely disabled individuals will not be living solely with other severely disabled or mildly disabled persons, but also with non-disabled persons in the mainstream of their communities. Strategies will will be developed, and resources utilized, to provide settings which foster growth and community identity.

SECTION SIX

AFTERTHOUGHTS

> In the real world, the "facts" are never all in and analyses and understandings are always imperfect. This is why action has to be based on judgement rather than deduction. This is also why there is often so much disagreement among people who share similar goals; their judgments of what should be the next step toward toe goal can vary widely. But though we all know these things - that our understanding is imperfect, that the consequences of what we passionately advocate today may be unanticipated or even undesirable - nevertheless, we must act as though there could be no doubt about what we do. The success of any program or social reform depends too much on decisiveness and confidence to permit the awareness of our human condition to dampen it. Thus, PL 94-142 (The Education for All Handicapped Children Act of 1975) has its enthusiastic advocates not because the law is "the" answers, but because it is perceived to be an important step in the right direction; and those who feel that the next urgent order of business is to create jobs for handicapped adults have their eyes on the immediate benefits to the economic and social status of handicapped people rather than on global economic factors. (Blatt, 1983, p. 329)

On Friday, October 12, 1984 an article highlighted the front page of the Syracuse Post Standard. Entitled "Teaching the Handicapped: High Hopes and High Costs," its underlying concern was with the rising costs of special education. Several special education professionals, stressed the impending financial and logistical barriers confronting continued integration of severely disabled students into public schools. Another, from the local Teachers Association, complained that the inclusion of these students caused distress among non-disabled teachers and students. No doubt. The mere sight of a severely physically disabled individual is enough to shock many individuals. Especially those who have never realized that such people exist outside of institutions and hospitals.

In the article, one special education administrator appeared quite content and reassured in her belief that severely disabled persons are now "out of the closet." Yet the "distress" these students cause only suggests they have been moved from one "closet" to another. They may among us, but they're hardly free from prejudice, misunderstanding, and alienation. Many severely disabled

students continue to spend the major portion of their "integrated" school days in segregated classrooms. Many believe its for their own benefit. However, many more are questioning that motive. Is it for their benefit, or ours? Is it because they need to be separated from us; or is it because we feel more comfortable and safe away from them?

This question used to be much more difficult to address. Segregated education was the cardinal rule for severely disabled students; there were no other options to consider and support. Yet, if little else, this report has shown that this is far from the case today. Study after study has demonstrated and confirmed the benefits of integration and community-based instruction. Their conclusions are not founded on hypothetical cases and characters, but true experiences across every corner of the country.

So the ideas I've generated through this research on aging out gain more credibility with each passing day. Whether they are realized depends greatly on the question posed in Burton Blatts words. Will we open our minds to the potential of severely disabled persons, or will we continue to suggest, as some of the professionals in the Post Standard article have, that administrative, financial, and logistical barriers make it an unreasonable effort? That the price for progress in this case, is simply too burdensome? For those who understand and believe in the concept of human potential, the answer is an unequivocal "no"! We have come too far down the road to abandon the future of our severely disabled brothers and sisters.

Joseph V. Miele, Jr.

Syracuse, New York

1984

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